

What is the British Paediatric Surveillance Unit (BPSU)?

The aim of the BPSU is to encourage the study of rare conditions in children. It was founded in 1986 by the Royal College of Paediatrics and Child Health, Public Health England and University College London GOS Institute of Child Health.

What does the BPSU do?

It allows doctors and researchers to find out how many children in the UK and the Republic of Ireland are affected by the particular disease or condition each year - this is called epidemiological surveillance. Doctors can also gather information about all the cases of a particular rare condition so they can begin to understand what might have caused it and how to diagnose and treat. BPSU studies can benefit future patients with rare conditions.

How does the BPSU work?

Each month the BPSU sends an orange card to over 3,800 consultant paediatricians and specialists; the card lists the rare conditions currently being studied. If any doctor has seen a child affected by one of these conditions they tick a box on the card and send it back. The BPSU informs the research team who send the doctor a short confidential questionnaire asking for more information. Researchers are not told the names and addresses of patients, and families are not contacted.

What has the BPSU achieved?

The BPSU has now helped to undertake surveys of over 100 rare conditions which may affect children. These have helped to increase understanding of why the conditions occur and can help to provide better diagnoses and treatments.

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Public Information Leaflet

Modern illness or a thing of the past?

How common is Sydenham's Chorea in children in the UK and the Republic of Ireland?

This leaflet provides information about a new study of Sydenham's chorea. It aims to provide information about the condition, why this study is important and what we hope to show by doing it. It also provides contact details of the researchers undertaking the study and a link to the website where the results will be published.

What is Sydenham's chorea?

Sydenham's chorea (SC) is a movement disorder, which can occur in children and young people. The main symptom is that the child cannot help making fast and irregular movements that they do not plan or want to make. Children and young people often also have emotional and behavioural difficulties, such as anxiety, at the same time. Symptoms may last for up to two years, and can have an impact on the child's ability to perform activities of daily living such as dressing, walking and writing. Although considered 'rare', little is known about the current pattern of this illness in the UK and the Republic of Ireland (ROI).

Why does Sydenham's chorea develop?

Children may develop Sydenham's chorea following an infection with the bacteria *streptococcus*. Sydenham's chorea may also occur as part of rheumatic fever, which is caused by the body's immune response to the same infection and involves joint pain, swelling and inflammation of the heart. However, it is not yet known why some children may develop the Sydenham's chorea following such an infection and others do not.

What are the aims of this study?

This project aims to answer the following questions:

- How many children with SC do paediatricians in the UK and ROI see over two years?
- What are the most common symptoms?
- How is the condition currently investigated and treated?
- How does SC affect the outcomes of children over a two-year period?
- What is the impact on their education?

How will the information be collected?

The BPSU researchers do not contact families or children with the condition. We will ask paediatricians to report when they see a child for the first time who has symptoms of SC, and then ask them to fill out short questionnaires when they first report the child with Sydenham's, and after 12 and then 24 months.

How will the information be used?

This study will provide us with more information on how many children are affected by this condition. Data collected will improve our understanding of the current problems associated with Sydenham's chorea. It will help us to identify the condition earlier and plan better services. All data collected will be held securely and confidentiality will be maintained at all times.

How to opt out of the research?

The NHS uses medical records for audit or research to improve future health and care. Hospitals and health professionals record when you do not want your child's notes to be used for audit or research so you must always let your child's consultant paediatrician know if you do not wish their medical notes to be used for research. If this is the case, your child's data will not be used in BPSU studies.

Personal data such as date of birth, hospital number and postcode will be collected by the paediatrician and transferred to the research team. However, only the direct care and research team will have access to this data. Transfer and storage of the data will be conducted within secure systems to prevent anyone else seeing this information.

Where is this study happening?

We will be asking paediatricians throughout the UK and Republic of Ireland to report cases to us when they see them.

How long will the study go on for?

The initial study will last for two years. We will then collect follow-up data from paediatricians about what happens to the cases they report for a further two years.

Who is funding this study?

This study is funded by the Paul Polani Award from the RCPCH and British Academy of Childhood Disability, and by the Sydenham's Chorea Association.

Who to contact if you have any questions

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Further information: www.rcpch.ac.uk/bpsu/sydenhams